

## CAREGIVER EXPERIENCE IN POTTY TRAINING CHILDREN WITH DOWN SYNDROME

Rifka Purnamawati\*, Zahroh Shaluhiah, Antono Suryoputro

Master of Health Promotion Program, Faculty of Public Health, Diponegoro University, Jl. Prof. Soedarto, SH, Semarang, 50275, Indonesia

### ABSTRACT

*Potty training assistance for children with Down syndrome is challenging because it takes longer to adapt and has physical and cognitive limitations. In addition, educating children with Down syndrome differs from one child to another. The study aimed to explore the role of parents or caregivers in teaching the potty training process to children with Down syndrome at States Special Needs School Semarang. The research was conducted using a qualitative phenomenological approach to determine parental participation in potty training in children with Down syndrome. Data collection was carried out by in-depth interviews and observations supplemented by field notes which were then transcribed verbatim. The search for informants used a purposive sampling method selected based on specific considerations with a total of 10 primary informants and those who cared for children with Down syndrome aged 7-14 years and were still in elementary school and two triangulated informants from teachers. Data analysis was carried out thematically. The results of the study found that the knowledge of most caregivers about potty training was limited to taking their children to the toilet, most of the children with Down syndrome were unable to urinate independently, the caregiver's difficulties when teaching potty training were problems communicating with the child, the caregiver's task in the potty training process was as follows: by finding solutions to make it easier for children to communicate and understand children's conditions. This qualitative research concludes that there is a theme regarding the role of caregivers with Down syndrome in potty training: caregiver knowledge about potty training, the behavior of children with Down syndrome during potty training, caregiver difficulties in potty training, and the caregiver's role or task in potty training.*

**Keywords:** *caregive, experience, potty training, down syndrome*

### ABSTRAK

Pendampingan potty training pada anak sindrom down merupakan hal yang menantang karena membutuhkan waktu lebih lama dalam hal adaptif serta mereka memiliki keterbatasan fisik dan kognitif. Selain itu, mendidik anak sindrom down berbeda antara satu anak dengan anak yang lain. Tujuan penelitian adalah untuk mengeksplorasi peran dari orang tua atau pengasuh dalam mengajarkan proses *potty training* pada anak sindrom down di Sekolah Luar Biasa (SLB) Negeri Semarang. Penelitian dilakukan dengan teknik kualitatif pendekatan fenomenologis untuk mengetahui partisipasi orang tua tentang *potty training* pada anak sindrom down. Pengambilan data dilakukan dengan wawancara mendalam serta observasi yang dilengkapi catatan lapangan yang kemudian dibuat transkrip dalam bentuk verbatim. Pencarian informan menggunakan metode *purposive sampling* yang dipilih berdasarkan pertimbangan tertentu dengan total 10 informan utama dan yang mengasuh anak sindrom down berusia 7-14 tahun dan masih duduk di sekolah dasar serta 2 informan triangulasi dari guru. Analisis data dilakukan secara tematik. Hasil penelitian didapatkan bahwa pengetahuan sebagian besar pengasuh tentang *potty training* sebatas mengajak anak mereka ke toilet, sebagian besar anak *down syndrome* belum dapat melakukan kegiatan berkemih secara mandiri, kesulitan pengasuh saat mengajarkan potty training adalah masalah berkomunikasi dengan anak, tugas pengasuh dalam proses potty training seperti dengan mencari solusi agar anak lebih mudah dalam berkomunikasi dan memahami kondisi anak. Kesimpulan pada penelitian kualitatif ini adalah adanya tema mengenai peran pengasuh *down syndrome* dalam *potty training*, yaitu: pengetahuan pengasuh tentang *potty training*, perilaku anak *down syndrome* selama *potty training*, kesulitan pengasuh dalam *potty training*, dan peran atau tugas pengasuh dalam *potty training*.

**Kata kunci:** *pengasuh, pengalaman, potty training, sindrom down*

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\* Correspondence Address: Rifka Purnamawati, Master of Health Promotion Program, Faculty of Public Health, Diponegoro University, Jl. Prof. Soedarto, SH, Semarang, 50275, Indonesia, E-mail: [rifka\\_purnamawati@yahoo.com](mailto:rifka_purnamawati@yahoo.com).

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## **Introduction**

Down syndrome is a condition of chromosomal genetic abnormalities caused by trisomy 21 (p21), where usually a person has 23 pairs of chromosomes from both parents or 46 chromosomes. However, people with Down syndrome have 47 chromosomes and are often found with health complications, and have poor mental and physical development left behind.<sup>1</sup> Down syndrome affects more than 300 genes, impacting numerous systems, is related to particular facial features, and is related to particular cognitive profiles.<sup>2,3</sup>

Based on data from WHO, it was estimated that there were 8 million people with Down syndrome. With an estimated incidence of 1 in 1,000 per birth, it affects around 3,000 to 5,000 births worldwide. Based on basic health research (riskesdas), the number of people with Down syndrome in Indonesia had increased from 2010 to 2018. In 2010, the number of children with Down syndrome aged 24-59 months was 0.12%, an increase in the 2013 Riskesdas by 0.13% and the 2018 Riskesdas by 0.21%. In addition, according to Riskesdas 2018, Down syndrome was the most significant contributor to disability among other types of disabilities, which was 0.21% of the total population of 57,361 people.<sup>4</sup>

Someone with Down syndrome has problems communicating with other people, especially children. Children with Down syndrome learn more slowly than others and have difficulty speaking and understanding other people's touch cues.<sup>5</sup> Children with Down syndrome experience delays in cognitive development between the ages of six months and two years. The cognitive capacity of children with Down syndrome is not comparable to children in general. Compared to other children of the same age, their cognitive abilities will decline rather than develop.<sup>6</sup>

In children with Down syndrome, carrying out daily living activities or self-development activities, one of which is potty training, is not easy and takes a long time because it requires motor movement, sensory, cognitive abilities, and sensorimotor coordination. In teaching potty training, a specific strategy must be adapted to the child's capacity so that the companion must have extra patience. Potty training teaches children to exercise control over urination, related to defecating and urinating at the right time and place. Potty training begins with an introduction to where the child should go to the bathroom (to the bathroom) until the child can clean up the remaining waste.<sup>7</sup>

Caregivers need to pay attention to potty training for children with Down syndrome. Because if potty training is performed late, as research from Dolva in Dreher et al. shows, delayed toileting is associated with adverse outcomes, including increased levels of internalizing and externalizing problems, social development, and social stigma resulting from the use of the diaper. The research shows evidence that boys with Down syndrome are slower to develop bowel or bladder control compared to girls with Down syndrome.<sup>8</sup> In addition, the average age of toilet training for kids and

teens with Down syndrome is 4.7–5.5 years, and it takes them 1.9–2.8 years to reach full toilet training compared to their peers without impairments (2.2 years; 6–9 months).<sup>9,10</sup>

The critical role of parents in caring for and educating children is to create an environment that is conducive to and supports the growth and development of children to improve the quality of life for children with Down syndrome and allows them to live independently.<sup>11</sup> One form of independence is the challenge of teaching children to urinate and defecate at the right time and place. The right place that turns out, which in reality is difficult to apply to children with Down syndrome. However, parents must remain motivated to encourage their children to get used to urinating and urinating at the right time and place, especially for children with special needs, such as children with Down syndrome.<sup>12</sup> This study aimed to explore the role of caregivers in implementing potty training in children with Down syndrome.

## **Methods**

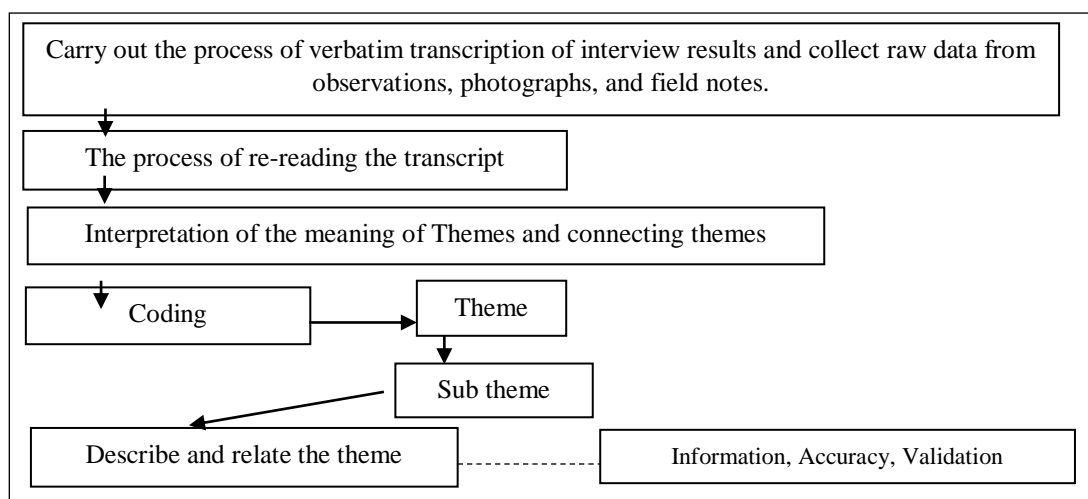
This was qualitative research with a phenomenological approach through in-depth interviews with informants according to the criteria set by the researcher. The search for informants used a purposive sampling method which was selected based on specific considerations, namely, the characteristics of the population were known and not randomly. The informants involved were parents or caregivers who directly cared for children with Down syndrome from birth until the research process was carried out. The ages of the children with Down syndrome who cared for them ranged from 7-14 years or sat in grades 1-6 of elementary school. As a condition for the validity of the research, interviews were conducted more than once, i.e., 2-3 times with the main informant. In contrast, triangulation informants were interviewed once, both by other adults who live at home with children with Down syndrome and by school teachers with children with Down syndrome. In addition to carrying out in-depth interviews with guidelines that have been made, the researchers also conducted observations of informants and children with Down syndrome by visiting the informants' homes to get an overview of the behavior of informants and children with Down syndrome.

The interview began with self-introduction, explanation of the purpose of the research, and giving the informant the opportunity to provide feedback during the interview process. This was done so that the atmosphere during the interview was not awkward and open so that the informant felt comfortable telling what he felt to the researcher. The interview began with questions about the informant's personal information, the potty training process for children, parental assistance, difficulties in potty training for children with Down syndrome, and additional questions where the interviewer asked the informant to develop his responses. The meeting ended with closing questions, allowing the informants to discuss other things they thought about but had never

discussed before. Researchers transcribed interviews and observations in verbatim form. All transcripts are uploaded to the NVivo 12 Pro Software to store, manage and organize data.

Data analysis was carried out with thematic analysis and characterized by creating sub-themes and themes through coding. Fulltext transcripts and replays to get a comprehensive understanding of the content. The next step was systematic coding to identify main parts, give full and equal attention to each piece of data, and identify aspects of importance that could be used to identify the theme. Researchers group these coded to create subthemes. The process involved comparing subthemes, codes, and repetitive interview texts. The relevant sub-topic contained information about the history of pregnancy.

The transcription results were then summarized. The analysis process was shown into the Figure 1.



**Figure 1. The flow of analysis**

This research has passed a research ethics review issued by the health research ethics committee, Faculty of Public Health, Diponegoro University, with number 354/EA/KEPK-FKM/2022.

## Results

The informants consisted of 10 caregivers who directly cared for children with Down syndrome aged 7-14 years. Based on the sex of the caregivers, there were eight females and two males with ages ranging from 28 to 54 years, with the last education from elementary school to university, with a dominance of senior high school. In this study, 8 out of 10 participants' occupations were housewives, unemployed, who directly cared for children with Down syndrome. All informants come from middle-class families. In addition, there were also two triangulation

informants who came from States Special Needs School Semarang Semarang’s teacher. More details can be seen in the following table 1:

**Table 1. Demographic Data of Research Informants**

<b>Participant</b>	<b>Age (years)</b>	<b>Gender</b>	<b>Last education</b>	<b>Profession</b>	<b>Caregiver Status</b>	<b>Down Syndrome Children's School Level</b>
I	41	Female	Diploma	Housewife	Biological parents	Grade 2 elementary school
II	48	Female	senior high school	Housewife	Biological parents	Grade 2 elementary school
III	40	Female	elementary school	Housewife	Biological parents	Grade 1 elementary school
IV	33	Female	senior high school	Housewife	Biological parents	Grade 1 elementary school
V	41	Female	senior high school	Housewife	Biological parents	Grade 3 elementary school
VI	54	Male	senior high school	Unemployment	Biological parents	Grade 2 elementary school
VII	34	Male	junior high school	Snack seller	Biological parents	Grade 4 elementary school
VIII	50	Female	elementary school	Housewife	Biological parents	Grade 5 elementary school
IX	47	Female	elementary school	Housewife	Aunt	Grade 5 elementary school
X	28	Female	senior high school	Housewife	Old Sister	Grade 6 elementary school
Triangulation Informant I (TI1)	37	Female	Bachelor degree	teacher	-	-
Triangulation Informant I (TI2)	52	Female	Bachelor degree	teacher	-	-

After reading each informant's in-depth interview transcripts and field notes, the researcher identified meaningful quotes and statements about the research phenomenon, then made specific keywords and themes and developed several keywords and subtopics. The formulation was consist of four themes what shown into the Figure 2.

The first theme is the knowledge of parents or caregivers about potty training. This theme explains what informants know about potty training. From the summary of the interview results, it

was found that what most parents or caregivers know about potty training is limited to asking their child to go to the toilet when they need to urinate or defecate.

*"...yes, practice going to the bathroom for the kids..." (I1)*

*"...I know it's asking to urinate or defecate in the bathroom; that's all I knew back then..." (I8)*

*"... when my child was three years old, I tried to take him to the bathroom; I squatted on the toilet, whether I felt like urinating or not, wanted to defecate or not..."(I9)*

In addition, some parents also try to find out from the school and child therapists about what and how to potty train their children.

*"...sometimes I ask the teacher and therapist for information on how to teach a child to go to the bathroom properly. I even asked the child's doctor, in the case of a child with Down syndrome, how to teach it..." (I2)*

*"... If I pay attention, my child catches it faster via YouTube, so I try to find a video about how to pee in the bathroom or if he wants to go to the bathroom to defecate...." (I9)*

Apart from that, the teacher at States Special Needs School Semarang as a triangulation informant also stated that education had been carried out, such as counseling to parents or caregivers regarding potty training for children with special needs, as seen in the statement of the teacher informant below:

*"... indeed, counseling is often given here to parents on how to teach children to go to the bathroom independently and how children can feel comfortable and calm about urinating in the toilet..." (T11)*

Most parents have taught potty training since their children were 3-4 years old, although some have done potty training over the age of 6 due to the physical abilities of children who are still unable to walk.

*"...my child has been going to the bathroom for about three years. So it is like being led to the bathroom; if she does not want to urinate, I still try to take her to the bathroom; whether she wants to urinate or not..." (I3)*

*"... if I'm not mistaken, it was the mother who taught my child to go to the toilet regularly at the age of 4, before she used diapers because sometimes she still wet the bed..." (I6)*

*“...I took my child to start going to the bathroom at the age of 7 years because he was only able to walk at the age of 6, so he was still wearing diapers until he was six years old...”(I4)*

The second theme is the behavior of children with Down syndrome when they finish the potty-training period. This theme discusses the ability of children to carry out the ability to go to the bathroom. Where according to caregivers that most of their children have not been able to carry out urination activities independently even though they have been given examples both verbally and in practice during the previous potty training period, as stated in the statements of several informants below:

*“... my child understands when he wants to pee; he's started to say pee...pee...During the day, he can say he wants to pee, but at night I still wear diapers now because sometimes he still wets the bed, he wakes up, but it is too late. Then for defecation, he is still assisted when washing because a child like him has rather short hands, so if he wants to wipe it, it is like his hands do not reach it, so I still help clean it. He has not been able to clean his genitals after urinating or defecating; I still teach him back and forth....” (I1)*

*“...If she feels like urinating, she already knows that by now and keeps running to the bathroom. It is just that she takes off her pants outside the bathroom because if in the bathroom, she often opens her pants to the bottom, hits the water, and her pants often get wet; then squats in the toilet, can flush and wipe after urinating or defecating, she actually can, it is just that I still repeat it, it does not feel clean...” (I2)*

The statement of the school teacher as a triangulation informant also supports this:

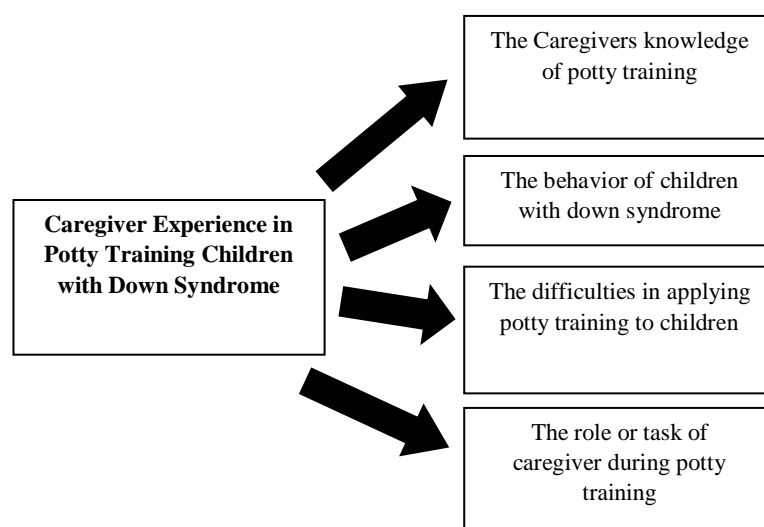
*“...the children can already express their desire to go to the bathroom, whether to urinate or defecate, but their abilities are still limited; they are not very clean, sometimes they find the water and still like to play with, their uniforms get wet, they do not return to class right away....” (TI2)*

The next theme is the statement from the caregivers who talked about their difficulties in applying potty training to children, where most of them were hampered by their lack of ability to digest directions, emotions, and communicate with children.

*“...I used to get emotional when my child did not understand what I was directing, actually, I understood my child could not understand what I was saying, but that is how it is, it is hard for a child to understand like this, it is even more difficult to tell a child when you feel like urinating or have a stomach ache, you want to go*

*straight to the bathroom, once at school, you wet the bed, right at this age, it is like you do not want to say that...." (I7)*

*"... sometimes when I tell her, I take her to the bathroom, I try to make it a routine to go to the bathroom; sometimes she does not want to; it is like she is not in the mood because she is so busy playing, so she prefers to pee in her pants. Once she pooped in her pants, whether she still did not understand what I was teaching her or was swamped playing it, I tried to tell her instead she was crying or angry...." (I9)*



**Figure 2. Four themes found in the study**

## Discussion

In this study, some Down syndrome children still have difficulty implementing potty training even up to elementary school age, so they need to be assisted by parents or caregivers in carrying out personal hygiene tasks, in line with previous research that there was a relationship between the role of parents and potty training, namely helping and guiding children to have a passion for learning because parents are role models and guidelines in their children's lives.<sup>13</sup>

In addition, potty training is essential for children with Down syndrome because they are gifted with cognitive and adaptive limitations; parents or caregivers are expected to continue to teach potty training repeatedly until they feel capable, even when they are adults, they are expected to be able to continue to accompany them in their implementation of personal hygiene. In children with Down syndrome, parents are expected to be able to help determine daily activities that can be introduced first, including going to the toilet. Creating a program of daily activities, such as parents or caregivers keeping a regular toileting schedule, and giving directions for going to the bathroom, are the most successful techniques in potty training.<sup>8</sup>



This research found that potty training was difficult for children with Down syndrome; for instance, potty training must still be carried out in terms of communication, physical abilities, and emotions. This was because parents or guardians help their children perform personal hygiene, especially for defecation and urination.<sup>14</sup> The role of the mother here becomes complex, such as in controlling defecation and urination in children with down syndrome, monitoring the physical and mental readiness of the child, supervising the child to develop a schedule for defecation or urination within 24 hours, reminding children to urinate or defecate, and as a model for teaching children to communicate when the stomach starts to feel uncomfortable, discomfort occurs when the sensation of defecation or urination arises, where the child must try to be able to convey the desire to go to the toilet, teach how to take off pants, teach sitting or squatting in the toilet bowl, including how to clean the genitals, clean the toilet, teaches to wash hands properly after removing dirt, and until wearing pants again.<sup>15</sup>

Another factor that influences the success of potty training is information received by parents or caregivers regarding potty training. Parents or caregivers also receive information from outside, such as child therapists and school teachers. Information about potty training is crucial because it influences the implementation of potty training for children, which is in line with previous research that parents who have knowledge about potty training will decide everything according to their children's abilities and motivation.<sup>16</sup> On the other hand, for parents who do not know about potty training, the application is not adjusted to the age and ability of their child, so this can cause anxiety, stress, and anger for parents when they see their child unable to go to the bathroom.<sup>7</sup>

Furthermore, according to research by Kitamura, caregivers who accompany children optimally will be more successful in achieving potty training than children who are not accompanied.<sup>17</sup> This shows the importance of the efforts of each caregiver in developing appropriate coping strategies to form an independent personality in children with down syndrome and be able to help themselves, especially during the toileting process.<sup>18</sup>

In this research, most parents or caregivers carry out potty training for children with Down syndrome in the age range of 3-4 years. Some even start at the age of 7 years after the child feels physically capable, which is slightly different from normal children. Previous literature suggests that for children without special needs, potty training occurs between the ages of 2 to 4 years when children are usually ready.<sup>19</sup> There is no definite age limit for starting potty training in children. It is just that the recommended age to start potty training is at least 18 months to 2.5 years when the child's neurological development is good enough, and the child's physical and psychological condition is ready.<sup>20</sup> The potty training process for children with special needs is similar to normal children. In a study by Mrad et al., the time to complete potty training was  $33.4 \pm 11.7$  months, and the average time to complete potty training for children with Down syndrome was  $56.2 \pm 12.6$  months.<sup>21</sup>

For children with special needs, the potty-training process is not much different from normal children, and the procedures and rules may not be much different or the same. This study found that most children with Down syndrome understood more about toileting activities in the form of direct practical instructions and are shown through pictures with interesting instructions and were repeated; this is in line with previous literacy that gives instructions to children through pictures related to steps or procedures. How to go to the toilet for children who cannot speak verbally is done repeatedly, and the child completes the potty-training process well.<sup>22</sup> It is also in line with research conducted by Istiqomah that using modeling techniques has a positive impact on children's capacity in potty training in children with cerebral palsy, both before and after the intervention. Parents introduce their children to potty training activities in addition to offering treatment with modeling strategies. The willingness of parents to devote the time needed to teach children with Down syndrome to use the restroom at home shows their readiness to provide such potty-training education.<sup>23</sup>

In this research, due to the physical and communication limitations of children with Down syndrome and the emotional readiness of children in the potty-training process, this is in line with research that the success of potty training can be assessed from two variables, namely internal and external factors which include psychological aptitude, physical abilities, and cognitive abilities in potty training. Potty training and developmental tasks (starting to learn to control urination and defecation in toddlers requires full support from the mother).<sup>24</sup>

The environment also affects children in implementing potty training. It was explained earlier that there were informants who felt they were not getting enough help when training children with Down syndrome through the potty training process. This is different from previous research conducted by Ambarawati and Susatyo, that the importance of social support, especially from partners, so that children can successfully carry out potty training such as carrying children to the bathroom, especially at night and when traveling, and conditioning children when they are fussy is very helpful in caring for children when urinating.<sup>25</sup>

Potty training will be successful if both parents and children cooperate. Parents and children will develop mutual trust if they work together well. According to several studies, a child's attitude, behavior, and way of thinking later when he is an adult will be significantly influenced by his recent experience. Potty training is essential in shaping children's character and forming mutual trust in the relationship between children and parents. The impact of parents not implementing potty training on children includes children becoming stubborn and challenging to manage.<sup>16</sup>

## **Conclusion**

The parents' experience teaching children with Down syndrome through the potty training phase. In this study, four themes were found regarding caregiver knowledge regarding potty

training, the behavior of children with Down syndrome during potty training, difficulties of caregivers in potty training, and the role of caregivers in potty training children with Down syndrome. In the future, caregivers with children with Down syndrome are expected to be able to explore the conditions of children with Down syndrome in terms of their ability in potty training.

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### **Conflict of Interest**

There is no conflict of interest in this research

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